



Life as a Laryngectomee

Patient Information Brochure

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Background

Cancer of the larynx (the voice box including vocal chords and epiglottis) is a rare disease and the incidence varies from country to country.

More than one hundred thousand new cases are reported worldwide each year accounting for less than 1% of all cancers. Compared to other forms of cancer, the treatment prognosis is usually good since the larynx is sensitive to very small changes and any change (i.e. growing tumor) is often heard or felt right away. This often leads to early detection and treatment. Common symptoms of laryngeal cancer include hoarseness, persistent coughing, problems with swallowing, soreness of the throat and/or pain in the ear.

Laryngeal cancer used to be much more common in men, but this is changing due to an increase among women. The cause of this cancer is not absolutely clear, although links to tobacco and alcohol have been established. However, both nonsmokers and nondrinkers have also been diagnosed with this form of cancer, so there may be other factors that contribute.

Laryngeal cancer and treatment

Depending on when the disease is detected, radiotherapy (radiation treatment), chemotherapy (chemical treatment), surgery or a combination of the three may be used to treat laryngeal cancer. If the tumor is too large or returns after radio or chemotherapy, it will probably have to be removed by surgery. This type of surgery is usually performed by an Otolaryngologist (ENT doctor) and often involves a total laryngectomy. The patient is afterwards referred to as a laryngectomee.

Edited by Jonas Karling, PhD, Speech-Language Pathologist, Stockholm, Sweden.

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What happens in a total laryngectomy?

Total laryngectomy means that the entire voice box and epiglottis are removed. In addition to voicing, these parts of the body also play a role in protecting the lungs. When eating and drinking, the larynx and epiglottis seal off the lungs during swallowing. So when they are surgically removed, you'll need another way to protect your airway. To accomplish this, the surgeon will permanently separate your windpipe from your esophagus. This will allow you to eat and drink without the risk of having food or fluids enter your windpipe and lungs. To accommodate breathing, the surgeon will attach your windpipe to a hole that is created in your neck. You will then do all of your breathing through this hole, called a tracheostoma or more commonly, a stoma.

The voice is lost

After a laryngectomy, your voice is lost. But this doesn't mean that you won't be able to speak. You can still form consonants and vowels even without your voice and the "listener" can to some extent read your lips. You can also use a pen and paper to communicate.

Losing your voice can be a traumatic experience for both you and your family. The voice is so much a part of your personality allowing you to express your thoughts and feelings and connect with other human beings. However, you have good possibilities to speak again. Thousands of laryngectomees can tell you so – with their own voices.

Respiratory problems are common

Losing your voice is not the only consequence of having a total laryngectomy. You will also be susceptible to lung problems because all of your breathing will be done through your stoma and air will no longer be passing through your nose and/or upper airway. We usually don't think about it, but the nose and upper airway serve a number of important functions:

- It is an extraordinarily effective heat and moisture exchanger, warming the air to 36°C (97°F) and humidifying it to 98% as it passes into the lungs.
- It filters impurities from the air.
- It provides us with the sense of smell and helps with taste.
- The distance between the nose and the lungs provides us resistance to breathing which is important for maximum intake of air.

After your surgery, your breathing will become shallow and the air you inhale will be dry, cold and unfiltered which makes your respiratory system extremely sensitive to the environment. You will likely experience an increase in coughing and sputum production as well as a decrease in energy. There are however good options to relieve these complications.



Smell and Taste

After a total laryngectomy, your sense of smell and taste will also be diminished. This is because your nose houses an organ called the olfactory epithelium and air won't be passing through this region anymore. The olfactory epithelium is mainly responsible for detecting odors but also plays a big role in taste (taste is affected by smell).

There are ways of learning to smell and taste again. Restoring these functions should be a very important part of your rehabilitation since without the sense of smell you might not be able to smell a danger signal, like gas or fumes. You will want to improve your ability to taste again since the enjoyment of food is an important dimension of your quality of life.

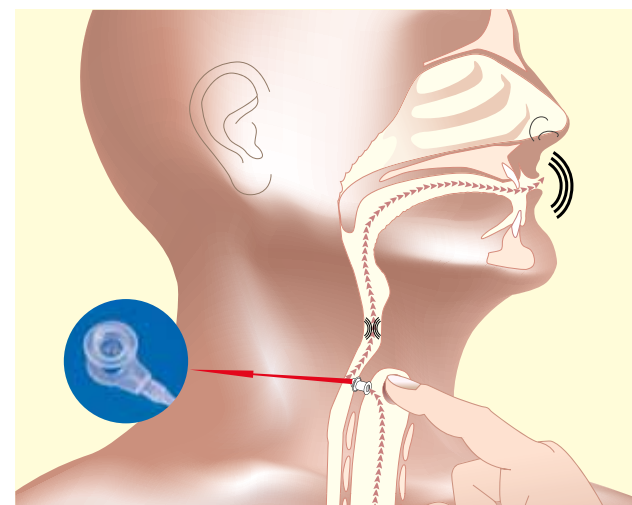
Three different ways of regaining speech

The first laryngectomy for cancer was performed in 1873 by a surgeon in Vienna. Since then, many methods of regaining speech have been developed, including artificial larynxes. Some of these early devices were reported to produce good sound, but problems occurred with the leakage of food and liquids into the windpipe and lungs, eventually resulting in pneumonia.

Since the early days, many advances have been made with voice restoration and today there are three major ways of creating a new voice:

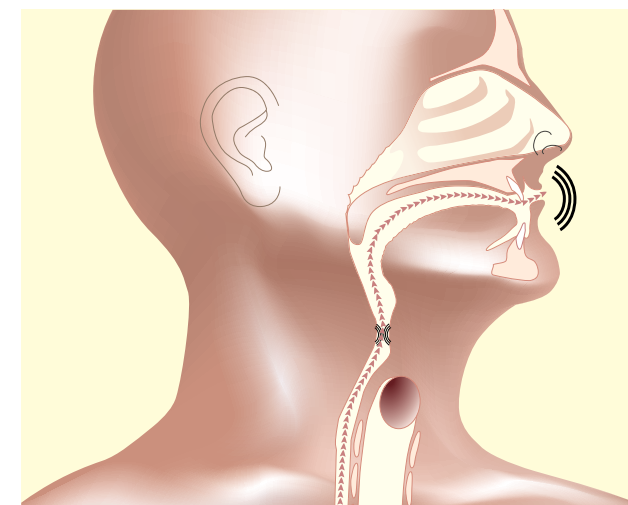
1. TE-speech with voice prosthesis

Worldwide, the preferred method for speaking after a total laryngectomy is known as tracheo-esophageal speech (TE-speech). In this method, a surgeon creates an opening (TE-fistula) through the wall of muscle that separates the windpipe from the esophagus (TE-wall). To prevent food and liquids from passing back into the lungs, a voice prosthesis is inserted into the opening. A voice prosthesis is a one-way valve that allows exhaled air to pass freely into the esophagus but closes during swallowing to prevent food and liquids from entering the lungs. To speak, you simply exhale while covering the stoma and the air from the lungs will be pushed through the voice prosthesis into the esophagus where a “pseudo” or false voice is produced. The two main benefits of this technique are that you can get your new voice fairly soon after your surgery and the qualities of the new voice will be closest to natural speech.



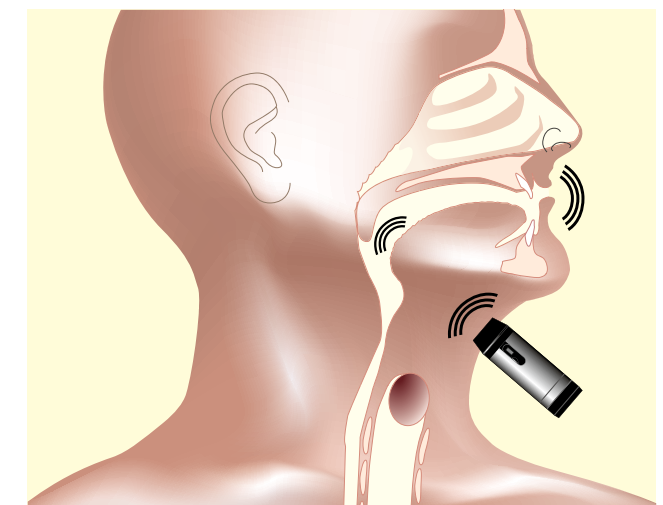
2. Esophageal speech

This technique is still practiced and works well for many people. The voice is created by swallowing air and then transferring it back up. From here, a “burp-like” tone is produced which can be articulated into discernable speech. Not all laryngectomees are able to master this technique. But if you can, it allows you to have “hands-free” speech at all times.



3. Electrolarynx

Another speech alternative is to use a vibrating electronic device called an electrolarynx. This device is usually placed on the neck or cheek region and transmits audible vibrations in the mouth that can be formed into speech.

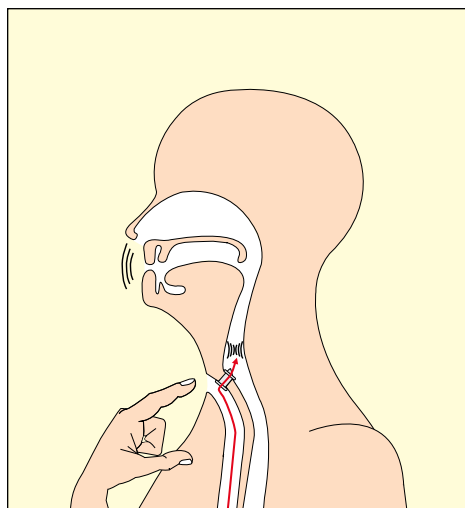


Provox® voice prostheses

How do I talk with a voice prosthesis?

Talking with a voice prosthesis can be easy but often requires some help from your Speech-Language Pathologist. Just like with normal speech, you use the air in your lungs and can alter your loudness and rhythm as you did before you had your total laryngectomy. Simply cover the stoma and gently exhale. The air is channeled through the voice prosthesis into the esophagus and a sound is created that will serve as your new voice. This new voice can then be articulated into discernable speech.

The quality of your voice will depend on the tone and flexibility of the muscles in your throat and esophagus. This means that it may take some time to create a good-sounding voice immediately after surgery because of swelling. Also, while talking, be sure not to press too hard against the stoma as this may obstruct the esophagus and make your voice not sound as good. In cases where the tension in your esophagus is too low, gentle pressure on the neck with your finger can help you achieve a good voice. As a general rule, you should avoid using too much effort since this can create tension of the neck muscles and make it more difficult to talk.



Provox® Vega™ with SmartInserter™



Since launching the first Provox voice prosthesis, Atos Medical has helped patients all over the world regain their right to speak. The third generation voice prostheses - Provox Vega Voice Prosthesis with innovative placement device, the SmartInserter, offers optimized air flow in three diameters; 17 Fr, 20 Fr and 22.5 Fr. All three diameters of the Provox Vega prostheses have been designed to maximize airflow to help reduce your speaking effort. Advanced design components of the voice prosthesis and cleaning accessories helps to prevent candida (yeast) problems.

Provox® (1) and Provox® 2



The first and second generation of Provox voice prostheses are made of soft silicone and can stay in place for extended amounts of time. Both prostheses feature a unique and sturdy construction and a low-resistance valve that is molded (instead of being glued) into the body of the prosthesis. The durable valve seals against a stabilizing, non-deformable hard blue ring made of fluoroplastic. Both the Provox (1) and Provox 2 feature stable flanges that keep them safely in place.

The Provox (1) and 2 voice prostheses can be inserted at the time of total laryngectomy, at a later time during a secondary procedure or anytime when needing replacement. Replacement is performed by a Speech-Language Pathologist, physician, or other health care professional who is trained in voice rehabilitation.



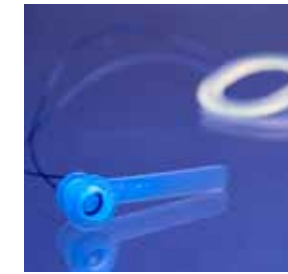
Provox ActiValve®



The Provox ActiValve is a special problem-solving voice prosthesis that should only be considered under special circumstances. The voice prosthesis is intended for those who frequently experience short device life of Provox (1) or 2 due to rapid and excessive yeast colonization and/or inadvertent opening of the valve during swallowing or deep inhalation.

The Provox ActiValve is placed by a clinician and contains magnets that actively hold the valve closed during swallowing. The prosthesis also features a valve and valve seat that are made out of a yeast-resistant material.

Provox® NID™



The Provox NID voice prosthesis preserves several innovative features of the Provox (1) and 2 but is intended to be replaced by the user. The Provox NID features low airflow resistance for easy and comfortable voicing, a built-in safety medallion to keep the prosthesis from falling down into the lungs, and the ability to be cleaned without removing it from the fistula.

The Provox NID can give some people greater control over the replacement and maintenance of their voice prosthesis however it is advised that patients consult their clinician for help in deciding if this patient-changeable voice prosthesis is right for them.

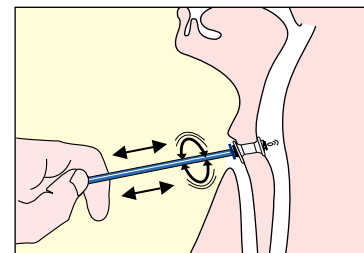
How do I take care of my voice prosthesis?

Sooner or later, silicone materials in the mouth and throat will be exposed to yeast (e.g. candida). If yeast begins growing on the valve of the voice prosthesis, it often cannot close tightly against the fluoroplastic seat. When this happens, fluids will start to leak into your windpipe when you eat and/or drink and it's time to have your voice prosthesis replaced.

Clinical research shows a large variation in the average device life of Provox voice prostheses. This is to be expected as human behavior and biology are also variable. Factors such as culture, diet, hygiene, prior exposure to chemo and/or radiation treatment and compliance with cleaning procedures can all affect the integrity and longevity of Provox voice prostheses.

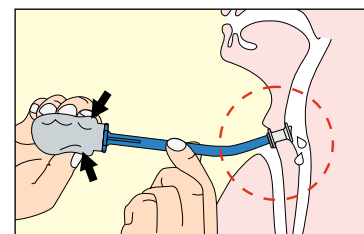
Provox® Brush

A special brush is available to clean the inside of your Provox voice prosthesis. The brush works to remove colonized yeast and debris and therefore can prolong the life of the prosthesis. To maximize results, you should use this brush at least once every morning and once every evening. Insert the brush into your voice prosthesis all the way to the blue retaining collar and move it back and forth while rotating it. This helps to remove particles of yeast, food and sputum from the valve and valve seat. If needed, the shaft of the brush can be bent which makes it easier to reach the voice prosthesis from many angles.



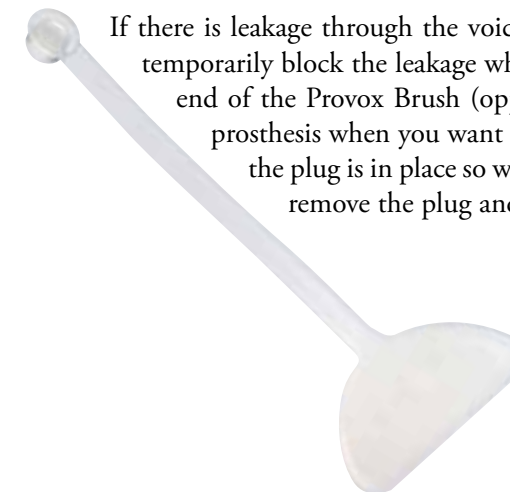
Provox® Flush

For additional cleaning, you can also use the Provox Flush. This device allows you to flush clean water or air through your voice prosthesis. When using the flush, it is important to seat the pointed end of the device firmly into the prosthesis and then hold it in place with your hand. Then use your opposite hand to squeeze the plastic bulb. After flushing, remove the pointed end from the voice prosthesis and a vacuum effect will suck any remaining water from the prosthesis and shaft of the flush back into the bulb.



Provox® Plug

If there is leakage through the voice prosthesis, you can use the Provox Plug to temporarily block the leakage while waiting for a replacement. Simply use the end of the Provox Brush (opposite the bristles) to place the plug into the prosthesis when you want to drink or eat. It is not possible to talk while the plug is in place so when you have finished your meal or drink, just remove the plug and you can talk again.



Leakage

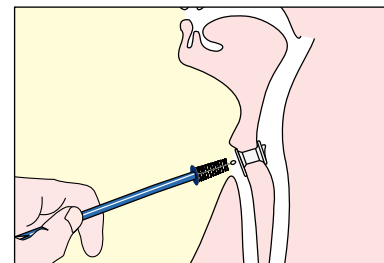
If you get leakage through the prosthesis and you cannot solve it by using the Provox Brush and Flush, the prosthesis must be replaced.

There can also sometimes be leakage around the prosthesis if the TE-wall has been weakened by radiotherapy and the TE-fistula doesn't form a tight enough seal against the outer shaft of the voice prosthesis. Also, if the prosthesis is too long, it can move back and forth, creating a pistoning effect that can force fluids around the outer shaft of the voice prosthesis and into the windpipe. There may be some ways for your doctor to address these problems:

1. Minimize the pistoning effect by choosing a prosthesis of the correct length; the tighter flanging reduces the pistoning and better seals the TE-fistula against the outer shaft of the prosthesis.
2. Remove the voice prosthesis and allow the fistula to shrink for some time. After acceptable shrinkage, re-insert a voice prosthesis of the correct size.
3. Tighten the fistula tissue around the prosthesis by using a simple suture technique or by injecting some medication that increases the tissue volume.

Fungus medication

In cases of high yeast, clinicians will often recommend antifungal medications. If this regimen is prescribed by your clinician, it is also safe to wet the Provox Brush with the antifungal solution and insert it inside your voice prosthesis. This should be done mornings and evenings and only after your voice prosthesis has been cleaned. In some cases, it can also help to swallow a few milliliters of the solution, but only if prescribed by your doctor.



Replacement

With the third generation of Provox voice prostheses (Provox Vega with SmartInserter) and also the Provox ActiValve, the replacement is a front-loading procedure that often takes a minute and causes minimal discomfort. Replacement can be done by a Speech-Language Pathologist, physician, or any other trained health care professional. The prosthesis is loaded into a conical insertion tube which folds the flanges down and forward. The insertion tube is then placed into the TE fistula and the prosthesis is pushed through the tube and into the fistula.

The Provox NID voice prosthesis is typically replaced by the user. First, the safety strap of the prosthesis is secured by a hinged lid on the insertion tool and then the prosthesis is pulled upward and positioned on the tip of the inserter tool. The Provox NID is then gently pushed and rotated into the TE-fistula.

How can I alleviate my coughing and lung problems?

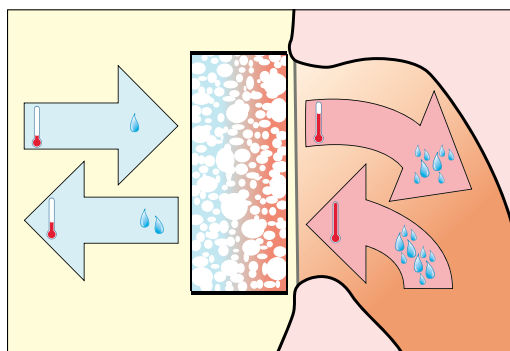
Heat and Moisture Exchanger (HME)

After a laryngectomy, your nose and upper airway are no longer working to “condition” the air you breathe. This often leads to excessive mucus and subsequent coughing, shortness of breath and a decrease in energy. However, if you wear an HME over your stoma, you will begin to relieve these complications.

- The temperature of the inhaled air will increase.
- The inhaled air will be humidified.
- Your “breathing resistance” will increase (this is very important for maximum utilization of the lungs).
- The “climate” of your breathing system will be constant and not as susceptible to seasonal changes or indoor/outdoor changes in temperature and humidity.

Multiple studies have found that regular usage of HME’s improves the quality of life. This is because you will cough less and produce less sputum. Conditions such as depression, anxiety, sleep deprivation and fatigue have been found to decrease while the social aspects of life improve.

You can also use an HME to help improve your TE-speech. Clinical research has shown that the quality of your voice can improve when you use an HME to occlude or block your stoma during speech compared to using your finger or thumb. Using an HME during speech also facilitates better hygiene since it prevents direct contact of your (dirty) thumb or finger to the stoma.



Provox® HME Cassettes



Provox HME Cassettes work by collecting moisture and warmth from the air you exhale and returning it to the air you breathe in. Another benefit of the Provox HME Cassette is that the air enters and exits through side openings, which prevents wet stains on clothing. This also prevents sheets or clothing from accidentally blocking the openings.

Provox HME Cassettes are available in two different types: XtraMoist™ HME and XtraFlow™ HME. The XtraMoist HME comes even closer to mimicking normal nasal function. Humidification is improved and good airflow is maintained for easy breathing. XtraMoist is recommended for patients who have recently undergone a total laryngectomy, and for those already accustomed to using an HME. XtraFlow HME delivers superior airflow. XtraFlow is great to use when exercising, when adapting to an HME, and for those that prefer lower resistance breathing. The cassettes are disposable and should be replaced at least every 24 hours.

When additional protection is desirable: The Provox Micron HME offers additional protection against small airborne particles, e.g. bacteria, viruses, dust and pollen. It is a good idea to wear a Micron when you are in a crowd, traveling by airplane, visiting a hospital, during cold and flu season, etc. The Micron couples the pulmonary benefits of an HME with an effective electrostatic filter.



Provox® FreeHands HME®



during speech but remains open during breathing. The Provox FreeHands HME also features an adjustable cough-relief mechanism, the ability to turn the valve “off” during physical activity, and three different membranes for adjusting the amount of force it takes to close the device for speech.

Base plates

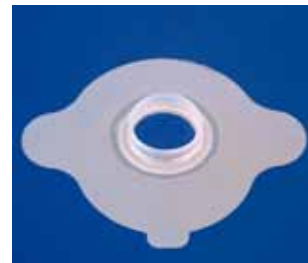
The Provox HME cassette is most often held in place by an adhesive housing (commonly referred to as “base plate”) that you attach over your stoma. The quality and shape of the base plate is very important since its primary purpose is to hold the HME and seal it tightly against your skin.

For some laryngectomees, air goes through the voice prosthesis easily (without too much resistance) and you do not have to pay much attention to strength of the attachment. Others, however, need base plates with stronger adhesion to avoid frequent replacements. Also, if the base plate does not stick to the skin tightly, some of the exhaled air will leak out during speech, resulting in a weaker voice and/or distracting noises.

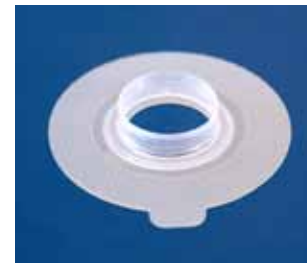
Adhesive base plates

The Provox Adhesive base plates are available in four different types, with three different adhesive properties and in two different shapes (oval and round). The types and properties include:

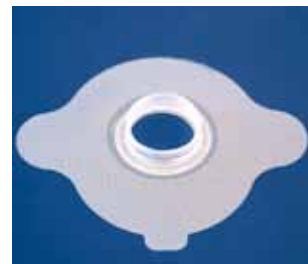
- OptiDerm™, made of a skin-friendly material. Can be used from the first day after surgery or for sensitive skin and can last for an average of 36 hours. This base plate is often preferred by people who experience irritation with conventional adhesives.
- FlexiDerm™, extra strong adhesive properties but more flexible than the OptiDerm. This base plate is the most commonly preferred and can last for an average of 48 hours.
- Regular, standard base plate. This easy-to-remove base plate can last for an average of 24 hours.
- XtraBase®, for deep or irregular-shaped stomas. This base plate features a unique shape and reinforced center and is also ideal for persons with deep stomas or anyone who uses an automatic tracheostoma valve such as the Provox FreeHands HME.



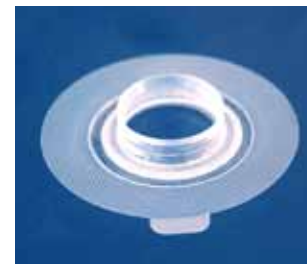
Provox® OptiDerm™, Oval



Provox® OptiDerm™, Round



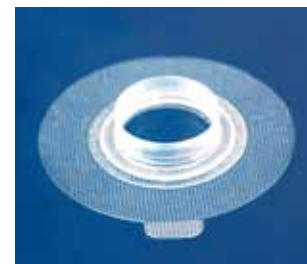
Provox® FlexiDerm™, Oval



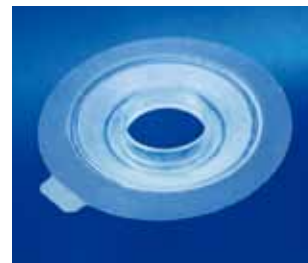
Provox® FlexiDerm™, Round



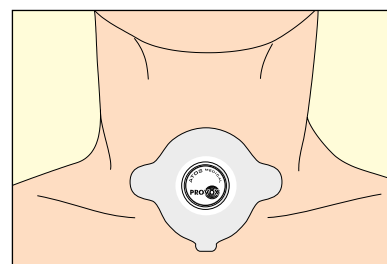
Provox® Regular, Oval



Provox® Regular, Round



Provox® XtraBase®



Is it possible to swim or take a shower?

After a total laryngectomy, swimming and boating can be risky. If you fall into the water, the stoma will not close automatically and you may drown.

It is possible however for you to safely shower. For comfortable showering, we suggest the Provox ShowerAid which attaches directly to Provox Adhesive base plates (FlexiDerm, Regular or a well-fitted Provox LaryButton).



How to keep the tracheostoma open

There are several different techniques surgeons use to create stomas, however the universal goal is to create a stoma that is stable and will not shrink. A larger stoma (diameter 15-20 mm) is usually preferred because it can allow for less troublesome breathing and easier replacement and maintenance of voice prostheses.

However, some stomas may still shrink. To prevent this, there are a number of different commercially available tubes. They can be made of metal, plastic or soft silicon materials.

Provox® LaryTube™

The Provox LaryTube is a soft and comfortable, transparent silicone tube available in several lengths and diameters and in three different versions:

- **Fenestrated** (with holes), if you use a voice prosthesis to communicate and your voice prosthesis and fistula are situated in a common position.
- **Standard**, if you don't use a voice prosthesis to communicate or if customized fenestration is needed to accommodate an unusually positioned prosthesis.
- **With Ring**, worn in combination with a Provox Adhesive base plate. This means that the tube can be inserted or removed while the base plate remains attached to the skin. This can be an advantage in the following three cases:
 - If you need to use a LaryTube but do not want to use a tube holder.
 - If you use base plates / HME's during the day but need to wear a LaryTube during the night.
 - If the combination of a LaryTube and base plate gives a better seal for regular or hands-free speech.



A key benefit that separates the Provox LaryTube from traditional laryngectomy tubes is that they can house an HME Cassette and/or automatic speaking valve. Until the Provox LaryTube was introduced, there had been no easy way of combining an HME or automatic speaking valve with a laryngectomy tube. Also, thanks to its conical and anatomically fashioned design, it seals tightly against the stoma when used during speech. So, if your skin is too sensitive for base plates and/or you frequently experience air leaks when talking, you may use a fenestrated LaryTube with a tube holder instead.

The Provox OptiDerm base plate is an optimal choice for housing an HME during the initial time after surgery or after postoperative radiotherapy when the area around the stoma is very sensitive. However, during the approximate six weeks of radiotherapy, if you still experience skin irritation with the OptiDerm base plate, your doctor can prescribe a LaryTube with tube holder for you to use. Keep in mind that you must not use any base plate during the actual radiotherapy sessions.



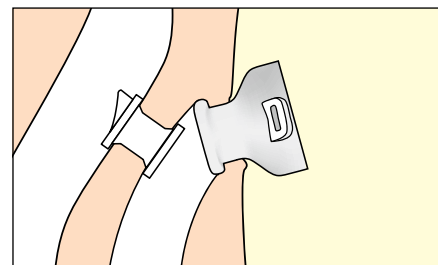
Provox® LaryButton™

The Provox LaryButton is a short, self-retaining silicone tracheal cannula. Just like the Provox LaryTube, it maintains the opening of the tracheostoma and acts as a holder for other rehabilitation devices of the Provox System including the regular HME cassettes and the Provox FreeHands HME.

Provox LaryButton is available in four different shaft diameters and two different lengths.

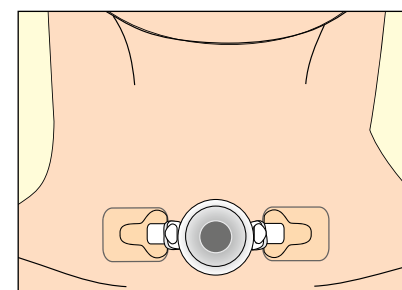
The main difference between the LaryButton and LaryTube is that the LaryButton is self-retaining in the stoma. Once inserted, it remains in position, taking advantage of the tissue elasticity of the tracheal opening which helps to hold it in place and provide an airtight seal. Of course it also helps to prevent the tracheostoma from shrinking.

If needed, wings which are attached to the outer rim of the Provox LaryButton may be used to secure the button with a tube holder / neckband in order to avoid accidental dislodgement.



Provox® LaryClip™

When an even more stable attachment is desired, you can try using the Provox LaryClip System. This system works to optimize the attachment of the Provox LaryButton to the stoma by using small rectangular adhesives in combination with a securing plastic clip. Simply apply an adhesive square to both sides of the stoma, attach the plastic clips to the LaryButton wings and then finally secure the base of the clip to the adhesive. Overall, the Provox LaryClip is designed to improve the chance for successful tracheoesophageal speech by helping to obtain a good seal of the Provox LaryButton to the stoma.



How can I regain my sense of smell and taste?

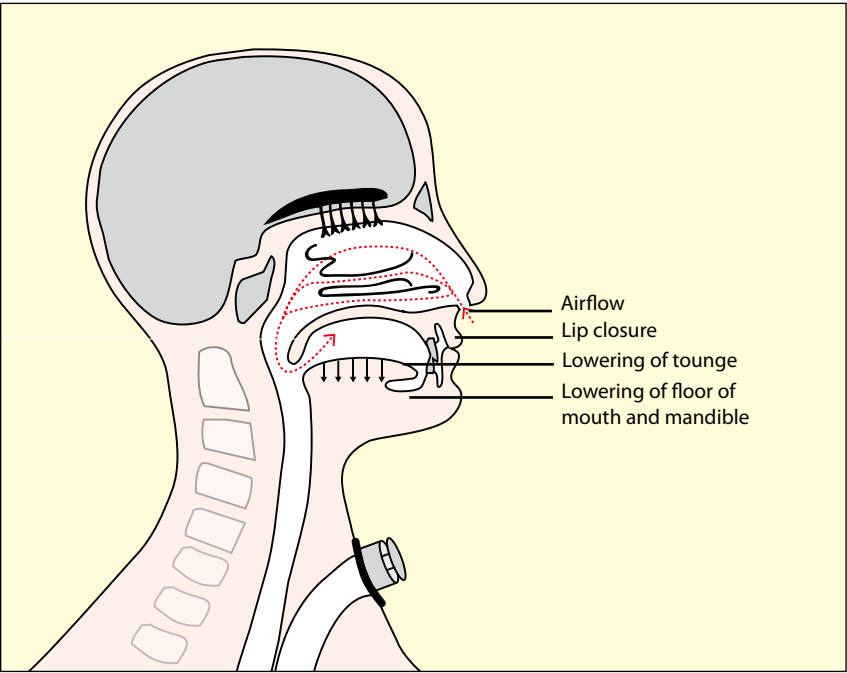
As mentioned earlier, the ability to smell and taste is a key part of our daily lives. Therefore, when these functions are diminished as the result of your total laryngectomy, it will be important to address them during your rehabilitation.

Many laryngectomees have learned to “politely yawn” when wanting to smell again. This technique is relatively easy to learn and involves discretely lowering and raising your jaw while keeping your lips closed. A vacuum is created in your oral cavity which then pulls air into your nose. You may also find extra smell when it’s windy. You can also try to “taste the air”, by letting air pass through your mouth and pharynx and then out through your nose.



move more air around in your mouth and up into your nose.

To maximize your chance for successful olfactory rehabilitation, have your Speech-Language Pathologist or health care professional contact Atos Medical for information on how to obtain the CD-ROM, “Olfaction regained, using the polite yawning technique.” Distribution by Atos Medical with the kind permission of the Netherlands Cancer Institute.



What’s next?

Are there others like me?

Although there are more than one-hundred thousand new people diagnosed with laryngeal cancer each year, not all cases require a total laryngectomy. However, many of these cases do and what this means though is that there are several hundred thousand laryngectomees all over the world. So, you are not alone!

In many parts of the world you can find laryngectomy support groups or “voice clubs” which are a great resource in helping you cope with being a laryngectomee. Many of these groups hold regular meetings where you can share your thoughts and experiences and benefit from the thoughts and experiences of others. These meetings can also be a good avenue for learning about the latest research, technology and/or newest products.

If you are not able to attend these meetings and/or do not have a group in your area, there are several on-line support groups and forums where laryngectomees from all over the world interact via the internet. Feel free to contact your nearest Atos Medical representative for more information on these and other support groups in your area.

Glossary

<i>Chemotherapy</i>	chemical treatment where toxic substances destroy cancer cells
<i>Esophagus</i>	the tube in your throat through which food passes into your stomach
<i>Exhale</i>	breath out
<i>Fistula</i>	a passage between two cavities
<i>HME</i>	Heat and Moisture Exchanger
<i>Inhale</i>	breath in
<i>Olfaction</i>	sense of smell
<i>Radiotherapy</i>	treatment where a radiation beam destroys cancer cells
<i>Stoma</i>	opening in the throat, exposing the windpipe
<i>TE</i>	tracheo-esophageal
<i>Trachea</i>	also called windpipe; the tube in your throat through which air passes
<i>Voice prosthesis</i>	a one-way valve that allows speech when exhaled air passes through it, while preventing food and liquids from entering the lungs during swallowing



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Atos Medical products and expertise are developed in close cooperation with leading institutions, doctors, researchers, speech language pathologists and patients from all over the world. All our claims and arguments rest on the results of clinical studies. Atos Medical started the research and development on the first Provox voice prosthesis in 1987. Throughout the years, we have worked hard to develop Provox as the leading voice and pulmonary rehabilitation system on the market. We continue to allocate substantial resources for product development and training programs for Ear, Nose and Throat specialties. Our goal is clear: Atos Medical will continue to lead the way in ENT.

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Leading the way in ENT